

**Testimony To**  
**Committee on Government Reform and Oversight**  
**United States House of Representatives**

**by**

**Judith Vukov, MD**  
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Mr. Chairman and Members of the Committee, I thank you for the opportunity to tell you of a tragic occurrence in my life that, I have learned, is all too common, in the field of scientific research.

My name is Judith Vukov, and I am not only a grieving mother but also a practicing psychiatrist and a provider of FDA approved psychiatric drugs. My twenty-five year-old daughter, Abby, died four and a half years ago. Fifty four days after entering the clinical trials for Resperidone versus Haldol, sponsored by Jansenn Pharmaceuticals and conducted by a UCLA team of researchers at the world renowned Camarillo State Hospital Research Unit 45, a satellite of UCLA/NPI. The clinical trials were headed by Dr. Robert P. Liberman who was also the head of schizophrenic research at the Los Angeles Veterans Administration and Neuropsychiatric Institute/ UCLA.

The official death certificate states that she died of aspirin toxicity and UNDUE DELAY IN DIAGNOSIS. In my opinion and that of many others this was a quick superficial explanation of why and how my daughter died. The emergency room notes, the urgent care notes and the sparse notes from Unit 45 serve to document that Abby was not only the victim of egregious medical malpractice at the emergency room and the urgent care but also the unwitting victim of fraud, misrepresentation and neglect by the research staff of Unit 45.

Abby died because she was placed at risk as a research subject and even when her condition became life-threatening she was neglected. The research records revealed that there was no attempt to intervene either medically or psychiatrically. The research staff, in an attempt to cover up their responsibility for her death have stated on numerous occasions that Abby took 300 aspirin while she was in my care, and even attempted to deny that she was the subject of research.

Last year I requested a full federal review of Abby's research experience and I have requested that the FDA place a moratorium on all research involving human psychiatric subjects at UCLA, the Veteran's Administration and Jansenn Pharmaceuticals until a thorough federal investigation can take place. I have heard nothing from the Food and Drug Administration.

An investigation by The California Health Department revealed in part that:

- (1) that there were no nurses or doctors caring for my daughter during the last 18 days of her life;
- (2) that the research team misrepresented Unit 45 as an “acute care unit” when in fact it was an “intermediate care facility” also known as a group home;
- (3) that she had been administered Tylenol thirteen times by the non-professional staff during the last week and that there were no physician notes explaining why;
- (4) that no treatment plan had been compiled during any of the 54 days she was residing on Unit 45.

On the night Abby lay dying 15 miles from the research unit the night staff recorded her as alive and well and in bed. Additionally, it appears from information received in a Freedom of Information request that the research team adjusted her diagnosis to fit the protocol requirements and ignored her extensive and serious medical history.

The Freedom of Information request revealed that:

- (1) to be included in the research one must have a clear-cut diagnosis of schizophrenia. The UCLA team ignored their own findings which were consistent with a mood disorder and the diagnosis of many previous psychiatrists, and labeled her schizophrenic so that they could use her as a subject;
- (2) the subject should not have been diagnosed with a neurologic condition. Abby had Tourette's Syndrome, Sydenham's Chorea and in the month prior to admission to Unit 45 she had been assaulted and had suffered a head injury on two occasions.

When Abby's condition deteriorated and dramatically changed for the worse as documented by the sparse records I was able to uncover, instead of reverting to standard practice the researchers utilized behavior modification and “shunning” a practice which had been outlawed by Los Angeles Patient's Rights years before.

After her death, the UCLA research team disavowed Abby as a research subject. However, under the Code of Federal Regulations altering her medication for the purposes of research automatically placed her in the research.

For Abby, the quality of care was more than deficient. My daughter was abandoned through neglect and traumatized by their particular brand of research.

The attitude of the UCLA team to my daughter's death and the findings of the investigations can be summed up in a statement by the head of the team during a fact finding event. When asked if he kept reports about Abby's death he said "if I saved all of the material that came across my desk there wouldn't be any room for me to sit down." Thus the findings about my daughter's tragic death only filled his wastebasket.

Speaking now as a psychiatrist I once believed that research subjects received the best care because the information passed on as facts to us in the field is what we base our informed decisions on. Based on what I have learned since Abby's death, I use every new drug with trepidation knowing that what was uncovered in the investigation of Abby's death and that of others is systemic and pervades all levels of the research community.

Abby's case was pivotal in the Los Angeles County decision to bar all conservatees from participation in research of any kind. To sum up my feelings and those of others, the LA Patient's Rights group said to me that if this had happened in a private hospital under their jurisdiction they would have shut it down.

Mr. Chairman, I am convinced that my daughter was only one of potentially thousands of mentally ill patients who have had adverse reactions to clinical research and then were simply abandoned and never reported to the FDA or to the National Institutes of Mental Health. There must be better monitoring systems in place to protect these people who are unable to protect themselves in the face of those who wish to promote the interests of science.